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FUTURE NEEDS AND DIRECTIONS FOR COMPUTERIZED RECORD LINKAGE IN HEALTH RESEARCH IN CANADA: FUTURE STUDY PLANS

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This paper plots some future directions for the use of record linkage in addressing some of Canada's health problems. It is divided into three main sections. The first section reviews some of the general objectives of current health studies. A list of specific projects which have utilized the Mortality Data Base since 1979, along with references to related published papers and technical documents, is used to illustrate the kinds of studies and products possible. (The reader is referred to Appendix 2 for the list of studies using the Canadian Mortality Data Base.) Several new ongoing studies which are just in the planning or pilot study phase are also listed. The second section outlines the kinds and broad functions of source records used and needed in future epidemiological and genetic studies involving delayed health effects. The third section describes some main directions for our future endeavours over the next 2-5 years,with examples from some ongoing or currently planned studies. To illustrate the type of projects possible, most examples are drawn from work using the Mortality Data Base file at Statistics Canada.

1. THE CURRENT STATUS

Since the last national workshop on computerized record linkage held in Ottawa in 1979, application and refinements to record linkage techniques in health research has progressed. It has demonstrated its enormous potential as a research tool for a variety of purposes. Some of these include:

* studying the mortality of specific occupational groups;
* examining the effects of medical procedures;
* determining the associations between suspected environmental agents and the health of those exposed to them;
* looking at lifestyle and other health risk factors, particularly those available in survey data files;
* creating provincial and national cancer incidence files;
* using provincial and national cancer incidence files for specific studies;
* carrying out genetic and demographic studies;
* creating new incidence data for specific disease conditions utilizing existing administrative data files;
* establishing a national monitoring system to detect associations between specific occupations and causes of cancer mortality;
* studying reproductive outcomes for specific groups;
* creating more complete individual work histories;
* creating individual exposure histories; and
* following up cohorts to determine the alive-or-dead status of individuals.

The objectives of several of the studies of the delayed

effects on health may be summarized as follows:

(a) humanitarian i.e. to assist in evaluating the efficacy of preventative and regulatory control measures in protecting human health from environmental hazards and to improve the quality of life;
(b) to improve scientific knowledge of the effects on health of various occupational, environmental and other conditions;
(c) to develop new computer methods for carrying out studies;
(d) to improve the quality, extent and timeliness of our statistical records;
(e) to reduce the cost and response burden in doing research studies; and
(f) to provide decision makers and health workers with relevant information needed for the establishment of health criteria and programmes for the setting of safety standards, and for the control of pollution and other environmental hazards in the workplace and elsewhere. Several of the current studies have been directly influential in socio-economic and regulatory decision making. Results from studies have been presented at royal commission hearings.

For the near future, it is anticipated that many of the studies will be updated to include additional years of follow-up; expanded to include additional members in the cohort file (such as rosters of existing new employees created at the time of hire for a company, or updates to surveys); and improved to include new endpoints, such as national cancer or other morbidity data files. Lessons can be learnt from examining the series of documents written regarding the legal, financial, organizational, and technical issues involved in setting up such studies (e.g. in the series of technical documents on the Eldorado Nuclear study, the Atomic Energy of Canada Limited study, and the Alberta Death Clearance).

If one were to single out one particular occupational study, the Ontario Miners' study by Dr. Jan Muller and his co-workers might stand as a model that other researchers might want to examine in initiating a new project. This study involved large numbers of miners in different types of mining activity, it used rather complex refinements in the linkage methodology, included an evaluation of the procedures being used, involved co-operation and collaboration of a number of agencies, and used rather sophisticated analysis of the resulting data. Additionally, the INCO and Falconbridge studies included independent follow-up of cases to evaluate the effectiveness of computerized record linkage techniques. Considerable experience has also been gained in compiling work histories from company records and in developing appropriate analytical facilities at McMaster University for these two studies. There has recently been an increasing demand for occupational studies by private industry. Expansion of this interest, especially for larger companies, may well continue, especially where government regulations require the monitoring, reporting, and retention of records where employees have been exposed to specific biological, chemical or physical agents. In certain cases, a third party such as the Epidemiology Unit of the National Cancer Institute of Canada is

carrying out the analysis of the data. It is anticipated that this trend for other independent organizations to do the analysis may continue.

2. THE FUNCTIONS OF BROAD CATEGORIES OF SOURCE RECORDS IN A "TYPICAL" STUDY

The kinds of records required for studies of delayed health effects may serve one of five possible functions in the follow-up process as shown in Figure 1. For future studies, not all of these files will be available in an equal degree. However, none of those that are available should be overlooked in preparing an overall study plan. Details regarding existing data sources and their suitability for linkage and use in occupational and environmental health studies have been documented earlier (A11, A17, A19).

First, such records may identify an individual as belonging to the exposed (or affected) population to be studied (or to a reasonably similar comparison group to serve as the unexposed (or unaffected) controls. In this case, they are referred to as "starting point" records which initiate the follow-up process. Where new data are being collected (e.g., on suspected high-risk groups), this should be done in such a fashion that it is possible to make international comparisons and to pool data (01-03).

Second, they may identify an end effect in an individual who is a member of the study population, in which case they are referred to as "endpoint" records. Examples of relevant data are: a) mortality data; b) birth defect monitoring surveillance programmes; c) health surveillance programmes; d) vital records, such as births; e) morbidity records; and f) cancer registers.

The third possible function of a record file is that of an intermediate file which facilitates the searching and the linkage process. For example, where a starting-point record carries the maiden surname of a woman who later married, and the endpoint record contains her married surname, the search of the endpoint file may be more productive and accurate where reference can be made to another file, such as a marriage file or the Social Insurance Number Index file which contains both of these names.

The fourth function of a record file is as a source of the detailed statistical variables required for the analysis. For example, linkage may be required to bring together individual work histories, exposure histories and lifestyle and confounding variables, such as smoking histories. One needs to have an idea of the general source of the likely end-points of interest, and where possible, some separation into different levels of exposure with which to investigate a likely dose-response relationship over time.

The fifth function of record files may be to serve in the evaluation process to indicate the reliability and accuracy of the data and the procedures being used. For example, an independent follow-up may be carried out with a sample of the records to

determine their true match status. Confirmation of dead-or-alive status may be possible using additional data sources.

3. FUTURE DIRECTIONS

For future developments pertaining to the production of new health statistics, priorities will need to be considered, along with some guidelines as to how these may be determined (A19). The extension of current facilities such as the Mortality Data Base will in general require justification largely in terms of the volume of the continued use which is made of it. The establishment of new facilities will , on the other hand, usually require justification in terms of the perceived need for their products. It is anticipated that there will be a demand for the development of national cancer files and other morbidity data, in addition to the mortality data now available.

When decisions are to be made concerning more significant new developments, it is envisaged that three types of benchmark questions may need to be asked:

(1) How great is the demand and how much use is the increased capability of developing the new files, facilities, and research projects being proposed; what are the anticipated benefits and risks of the proposal; and how will the results be be communicated and marketed?

(2) Are the details of the proposal technically sound and how good is the evidence that they are? Could a researcher obtain this information elsewhere?

(3) How much will it cost initially and how much will subsequent users and researchers benefit from this work, and how much will they have to pay, or perhaps save, because of it?

Over the next few years several major multi-year projects are being planned. For example, the farmers and the national dose registry studies both involve a series of different linkages using a number of different files. Where major projects are being developed, exploratory testing and improvements may first be required to indicate where there is any major technical impediment to a large-scale computerized linkage operation. After that, a larger "pilot study" may be encouraged for the purposes of documenting in some detail, the steps and projected costs (e.g. mortality after the death of a spouse study, the census - infant death linkage project).

As described earlier (A21), there are three main directions for our future endeavours: (1) The improvement and expansion of existing search and linkage facilities which could include further development and enrichment of our current files (e.g. addition of occupation and industry on the death file, addition of complete birth year for earlier death years, data capture of additional parental names and birth dates as well as name of spouse). The NYSIIS (01) phonetic code routine needs to be evaluated more fully, taking into account the kinds of names found in Canada. The usefulness of encoding forenames needs to be explored. The use of a series of identifiers

for multiple passes of the files needs to be more fully evaluated. A dictionary of accredited comparison procedures needs to be developed from past linkage studies that could serve as a guide for future studies. Results from earlier studies need to be carefully evaluated, particularly with respect to the use of intermediate files and the use of alive follow-up procedures as were used in the Ontario miners study. Further refinements are needed in developing the file of nonlinks to get weight estimates, particularly where the comparisons are fairly complex (e.g. weighting of forenames). A model project needs to be set up to facilitate training of new personnel. A handbook of procedures to be followed in carrying out record linkage projects would be extremely useful, particularly for new agencies setting up projects for the first time. Additional courses for provincial and other agencies interested in this type of activity may also be useful. (2) The development of new and much needed data bases which would identify, in a more systematic fashion than heretofore, the occupational and environmental circumstances of people and which could be used as starting point files, to initiate searches for subsequent health histories. Here data collection rules and forms which could be used by industry need to be more clearly developed and tested. Use of new files such as census of agriculture, farm registers, and census of population files can be exploited. The use of existing files for alive and morbidity follow-up need to be explored and tested. (3) The exploration with other agencies of any collaborations that would be productive for generation of the required statistics to address current and emerging health issues, and for setting up the necessary communication network and financial support to implement such recommendations. Results from a number of studies are being compared, and in certain cases international groups of epidemiologists are combining data from relevant health studies (e.g. for nickel workers, and also for radiation workers) for a single analysis. Certain small-group populations, identified through specific findings, may be appropriate for national and international collaborative investigations. Here it is important that standard guidelines be used in setting up and carrying out the studies.

4. ACKNOWLEDGMENTS

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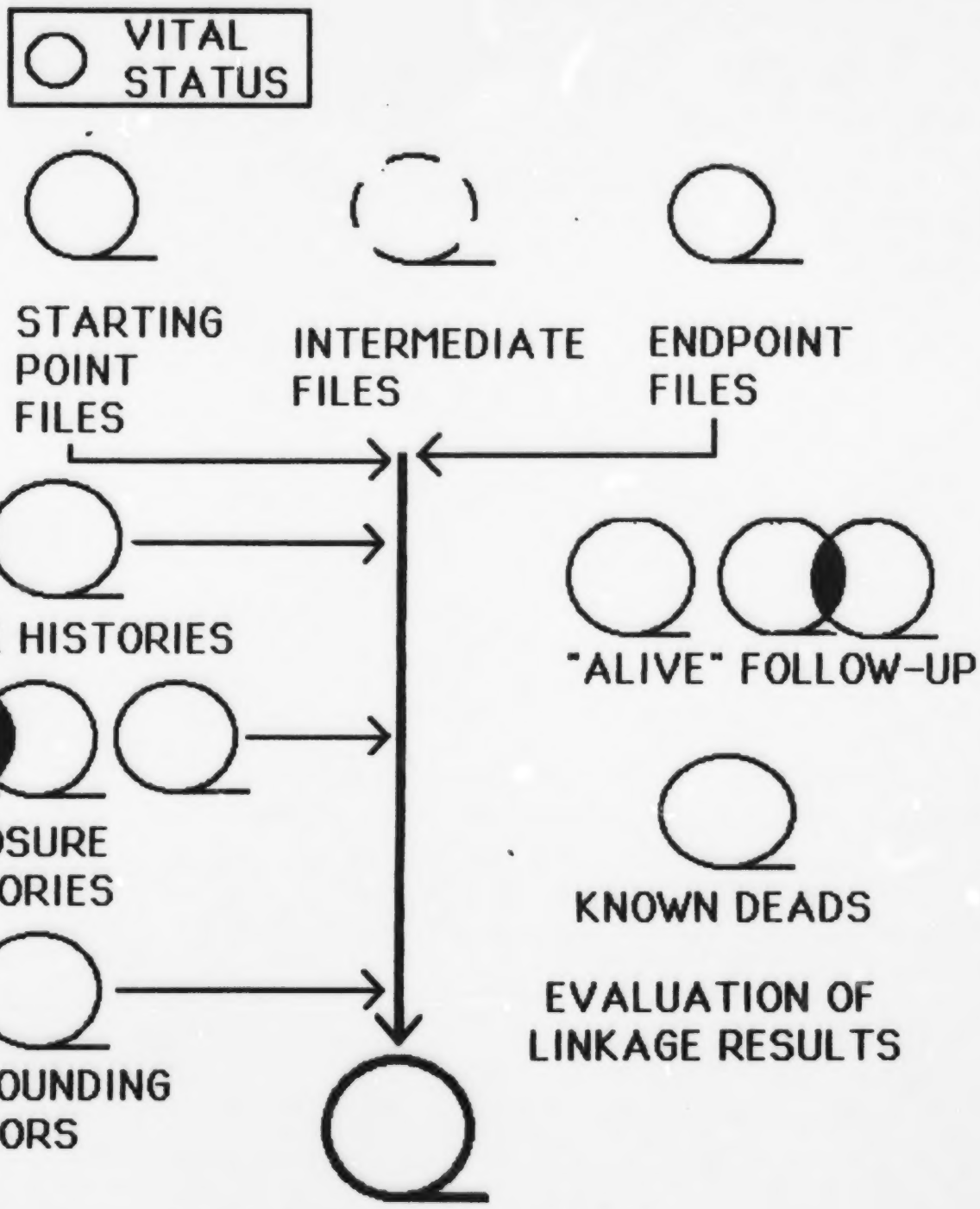
THE FILES
IN A " TYPICAL " STUDY



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